HUNTINGTON'S DISEASE
YOUTH ORGANIZATION

Enroll-HD

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HDYO has more information about HD available for young people, parents and professionals on our site:

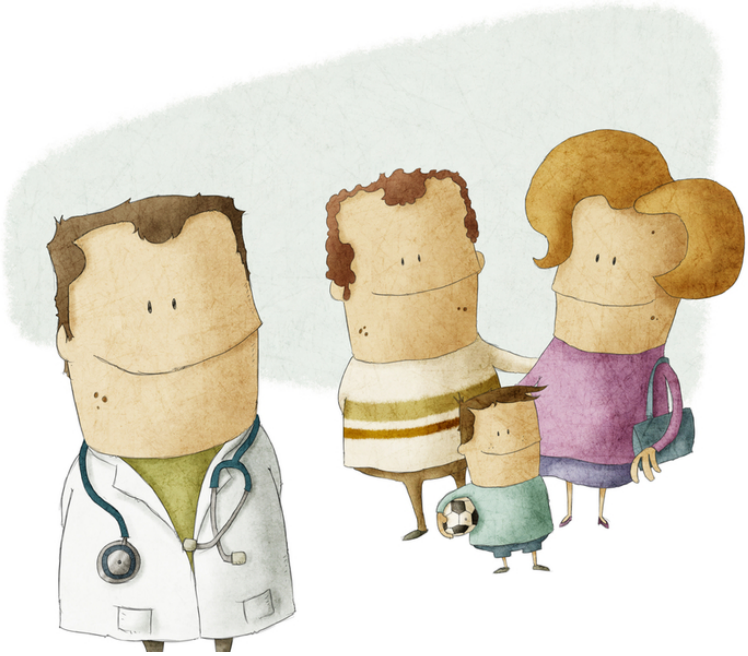
www.hdyo.org

Enroll-HD: A study the whole family can participate in

What is Enroll-HD?

When it comes to HD research studies **Enroll-HD is perhaps one of the most significant studies there will be**. Enroll-HD, in simple terms, is an observational study, which means there are no drugs involved; it is purely a study to 'observe' and gain knowledge about how HD works. To do this, participants are only required to attend one appointment each year which lasts about an hour. During this time, a number of tests are done and then the results of which are put in to a massive confidential database to be analyzed by researchers from around the world to understand better how HD works and what treatments may work for HD in the future. The scale of Enroll-HD is phenomenal, some of you may have heard or even participated in the observational studies Registry (European study) and COHORT (North American study) which had over 10,000 participants between them. Enroll-HD essentially merged these two large studies while expanding the scope even further and bringing in more sites around the world in place such as South America, Asia, Australasia and Africa where people can take part in Enroll-HD. Enroll-HD can boast about being by far the largest HD study in the world and it is large for a good reason: The more people that participate in Enroll-HD the more we understand how HD works and how to treat it. Currently, it has more than 21,000 people enrolled!

Why is Enroll-HD so important?



Observational studies for HD can tell us a lot about what roles our genes (DNA) plays in how the condition progresses. These studies can also tell us interesting things about what role the environment plays with regards to HD. For example, we know that two people with the same CAG expansion can develop symptoms of HD at completely different ages, many years apart. But we don't yet fully understand why that happens - what causes one person to develop symptoms at 40 and another to go another 20 years without symptoms? Due to its global size, Enroll-HD can give us vital answers to questions we simply were not able to even consider answering before. In previous decades, observational studies of HD have been small in number and because of this the results have not been clear enough. Enroll's global participation means that everything is taken into account (genetic and environmental) and we can gain far better insight into HD than ever before.

Secondly, Enroll-HD works as a register for clinical trials and other HD studies. When people participate in Enroll-HD, their data goes onto one massive confidential database, which is very helpful if you are a researcher and you want to do a clinical trial on a possible treatment for HD and you need a specific type of people. Suddenly, thanks to Enroll-HD, researchers have a huge database of potential participants ready to contact. Whereas before it would have taken a very long time to find enough people to participate in the trial, now it takes significantly less time to start trials because researchers can search the Enroll-HD database for the right people for that study and invite them to take part. This means that recruited for clinical trials will be a lot quicker and people with HD will get treatments quicker, due to Enroll-HD.

> **'Basically, it lays out a "Welcome" mat for researchers and pharmaceutical companies to study HD, supplying many of the essential ingredients for a clinical trial, such as a global network of research sites, a carefully maintained database that tracks people's health over time, and, most importantly, an up-to-date anonymous database of people who have HD or the gene mutation who might want to volunteer for a new study. You can home in on the group of people who are likely to be eligible for a study or trial and these individuals can then be invited to join by their own doctor. You make the work much more efficient.' says the principal investigator for Enroll-HD**

Who can participate?

The amazing thing about Enroll-HD is that any member of a family affected by HD can take part, whether you are at risk, tested positive, tested negative, symptomatic with HD and even partners not at risk. It's a very accessible study in that sense, we can all contribute to the battle against HD by giving some time to go to our local Enroll-HD site and participate once a year. Everybody can get involved and make a hugely significant difference by participating in Enroll-HD. The criteria of those who can participate includes:

- Individuals who know they carry the expanded gene, whether or not they show signs and symptoms of the disease
- Individuals who are at risk of developing the disease (but have not undergone genetic testing)
- Individuals who have a family history of HD but know they do not carry the expanded gene
- Spouses/partners (not blood-related) of family members with HD
- Children under the age of 18 with clinically diagnosed juvenile HD may be included in this study with the consent of a parent or legal guardian.

What is involved?

Enroll-HD is an annual appointment. Once a year, participants are asked to visit their study site and perform some tests. The tests performed in the Enroll-HD study include:

Blood & urine samples: Blood and urine samples are analyzed to help learn more about the genetic aspect of the disease. The data can also be used in future studies to help further knowledge of the disease and search for potential treatments.

Thinking (cognitive) tasks: These involve doing a lot of tasks that seem more like games than tests. But they are in fact measuring different aspects of thinking, like attention, memory, and problem-solving.

Motor (movement) and behavioural tests: Participants are also asked to perform a series of movement and behavioural tasks, which are very common for any Huntington's disease research study. This exam includes things like: walking in a straight line, following movements with your eyes, tapping your finger and answering a series of questions to help get a sense of your state of mind.

It is important to say that you are in complete control at an Enroll-HD appointment. If you don't want to do something, let your study site know. If you want to stop the appointment, you have complete control to do that too. Obviously, the study site would like you to participate fully, but if for whatever reason that is not possible then that is perfectly ok.

Learn more about what an appointment for Enroll-HD looks like here.

How can you enroll in Enroll-HD?

Taking part in Enroll-HD is made easy by the cool website they have for the study which provides a world map with all the sites they do Enroll-HD on it. You can find your nearest site and their contact details, from there all you need to do is give them an email or a call. Visit the Enroll-HD site at enroll-hd.org.

Make a difference for your family and the wider community of families impacted by HD and take part in this simple study that will hopefully provide key answers for HD research.
